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### **Meningococcal Outcomes Study in Adolescents and In Children**

**Commissioned by Meningitis Now and led by Prof. Russell Viner, UCL Institute of Child Health**

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#### **Aims of the study**

- to measure the physical, psychological, social and economic burden of meningococcal group B disease (meningitis and septicaemia)
- to estimate the after care needs of those affected to support the development of a nationwide standard of care and ensure Meningitis Now is providing the support that is needed
- to collect information that can be used to support the need for, and introduction of, a meningococcal group B vaccine.

From May 2008 to September 2010, 573 children and their families, from across England, took part. 245 children (cases) had suffered meningococcal group B disease (MenB) three years previously, when they were between the age of one month and 13 years. The other children (controls) had not suffered MenB. All children were assessed in the same way so that an accurate comparison could be made between the two groups. Each person's experience of the disease will be slightly different, but the following results show the *average effects* of MenB.

#### **Results**

##### **Cognitive skills**

Children and young people who have survived MenB are significantly more likely to have:

- a borderline low IQ (<85), both verbal and non-verbal
- deficits across all aspects of memory and sometimes in multiple aspects
- poorer executive function leading to difficulties with organisation and planning

## Physical

The following physical limitations and after-effects were reported in the survivors of MenB:

- hearing loss – five times more likely to have a significant hearing impairment, with 2.4% survivors having bilateral hearing loss requiring a cochlear implant
- amputation – significant amputation with disability in three cases and finger/toe amputation in a further two cases
- epilepsy – significantly more likely compared to controls
- speech and communication difficulties – five times more likely compared to controls

## Mental health

One in five children and young people who have survived MenB have anxiety and behavioural disorders.

## Summary

More than a third of children who have survived MenB experience difficulties with cognitive, physical and/or psychological function.

## How will the results be used?

- the results of this unique study have already been presented, as evidence of the burden of MenB, to the Joint Committee on Vaccination and Immunisation (JCVI). This is an independent, expert advisory committee that advises the Department of Health on the provision of vaccination and immunisation services
- the results were used by Meningitis Now to support a campaign (launched October 2011) for regular educational assessments for all children and young people who have had meningococcal disease
- The results will also be used to inform health and education professionals about the long term impact of Men B so that children and young people are effectively supported

## Support for life

Meningitis Now provides support for life to anyone living in the UK who has been affected by meningitis. If you have concerns or would like support you can call our helpline 0808 80 10 388 or visit [www.meningitisnow.org](http://www.meningitisnow.org) to find out how we can help you.

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